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Termination for Fetal Anomaly: What is The Impact of Genetic Counseling on Coping?

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TERMINATION FOR FETAL ANOMALY: WHAT IS THE IMPACT OF GENETIC COUNSELING ON COPING?

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TERMINATION FOR FETAL ANOMALY: WHAT IS THE IMPACT OF GENETIC COUNSELING ON COPING?

A

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Pregnancy termination for fetal anomaly (TFA) is a unique experience that can cause women to develop long-term, complicated grief. Although a woman's experience with her healthcare providers has been previously identified as an important factor in coping, studies have shown that many women report their healthcare as lacking to some extent. Given the overlap in patient needs and the practice scope of a genetic counselor (GC), this study aimed to examine how genetic counseling may impact coping as well as explore patient expectations of GCs pre- and post-TFA. An online survey, which included the Brief COPE and The Short Version of The Perinatal Grief Scale, was distributed among private, online support groups. Appropriate statistical analysis tools, such as the Wilcoxon rank-sum and t-test, were utilized for quantitative analysis of the 124 responses, and thematic coding was utilized for qualitative analysis. Of participants who underwent TFA within the last two years, women who saw a GC utilized active coping, planning, and positive reframing significantly more than women who did not see a GC ($p=0.001$, $p=0.031$, $p=0.027$, respectively). GCs were perceived to have a positive impact on coping when providing information, objective care, emotional support, support resources, and follow-up care; these practices encouraged confidence in decision-making and gave participants hope for the future. This study not only identified key counseling roles for GCs prior to a TFA, but also demonstrated that genetic counseling prior to TFA may be beneficial to patient coping. Further studies are warranted to explore the needs of a more diverse patient population and to identify appropriate genetic counseling training methods to support those patients pursuing TFA.

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Introduction

The diagnosis of a fetal anomaly during pregnancy is often unexpected and may shatter a woman's expectations for a normal pregnancy. In such circumstances, women face several decisions and the option for pregnancy termination for fetal anomaly (TFA) may challenge previous views on termination and lead to feelings of guilt (Benute, 2012; Maquire et al., 2015). For some, TFA is considered an emotionally traumatic major life event as the psychological implications can be quite burdensome (Kersting et al., 2005). Previous studies have identified that this perinatal loss can often lead to complicated grief, post-traumatic stress, and depression in women and their partners (Kersting and Wagner, 2012). While these psychological repercussions can be long-term, the first two years following a major life event have been identified as the most significant period of the grieving process (Badenhorst & Hughes, 2007; Macieiewski et al., 2007). Frequent themes intensifying grief can include self-blame about the diagnosis, guilt stemming from the decision to end the pregnancy, social isolation and triggering experiences, whereas time and social support can act as mitigating factors (Maquire et al., 2015). Utilizing adaptive coping mechanisms following TFA has also been identified as having a positive impact on psychological outcomes (Lafarge et al., 2013).

Though women often note seeking support from their significant others, families, and friends, an additional type of support may be an individual's healthcare provider(s). Their interaction with their provider(s) has been previously identified as an important factor that can impact a patient's ability to adjust post-procedure (Asplin et al., 2014). Lafarge et al. (2017) found that most healthcare providers were able to acknowledge the importance of support systems as well as identify key coping strategies, such as avoidance, problem-solving, and acceptance, that women may utilize shortly after TFA. However, while both individuals who underwent TFA and their healthcare providers acknowledged that this experience involves complex, long-term grieving, there was insufficient understanding of the long-term coping process and the expectations for their healthcare providers in follow up care. Studies focused on women undergoing TFA have identified that most have not considered their individualized need for support at the time of the procedure and may not yet realize or be able to advocate for their

long-term support needs (Ramdaney et al., 2015). With little information known about the expectations or support needed by these individuals, it may be difficult for providers to determine how to best care for women undergoing TFA and what may be beneficial versus detrimental to their coping process. Additionally, there are no specific guidelines for healthcare providers to follow when providing care to women in such circumstances.

In fact, research indicates that a number of individuals who have undergone TFA feel that their healthcare experience was lacking to some extent (Fisher and Lafarge, 2015). In a study by Slade et al. (2001) that surveyed women in the process of undergoing a first trimester termination of pregnancy, a significant portion of study participants reported feeling that the healthcare providers they interacted with did not adequately listen to their concerns in addition to some participants reporting concerns about healthcare providers' behaviors, which included a lack of support, overly clinical care, or feeling criticized by the provider. More recent studies have also begun to shed light on the importance of care that goes beyond just the termination procedure itself. In a cross-sectional study by Fisher and Lafarge (2015), women not only commented on the importance of seeing experienced, well-trained professionals, but that it was crucial to see providers that were compassionate and able to acknowledge the unique circumstances behind TFA in order to empower them to make informed decisions and seek support resources. Overarchingly, the "human aspects of care" are what women report as being the most important factors in their healthcare experience. These include communication, understanding and compassion, and support throughout the process. Individuals who have undergone a TFA have also cited a desire for more organized follow up and additional identification of resources as needed aspects of their care (Asplin et al., 2014).

Many of the cited aspects that these women are looking for in their healthcare providers are those that correspond with the scope of practice of a prenatal genetic counselor. Prenatal genetic counselors are trained to educate the patient about the identified anomaly, facilitate understanding and informed decision making, advocate for the patient, identify support resources, and recognize and address

psychosocial concerns (Resta et al., 2006; Accreditation Council for Genetic Counseling, 2013). Although there is more to learn about women's needs in the long-term coping process, it is clear that healthcare professionals have the ability to impact a woman's experience surrounding a TFA and her initial ability to cope. As such, the significant overlap in a genetic counselor's scope of practice with the identified needs of women in regard to their health care experience would suggest that seeing a genetic counselor prior to undergoing TFA may be beneficial.

To date, there has not been a study that explores the impact of genetic counseling on a woman's self-perceived ability to cope post-TFA. Therefore, our study aimed to assess if there is a significant difference in ability to cope post-procedure between women who see a genetic counselor and women who did not see a genetic counselor prior to their TFA. Additionally, we explored factors that lead patients to accept or decline genetic counseling prior to a TFA and expectations for future genetic counseling appointments. The intended impact of this study is to better understand the needs of this population in order for genetic counselors and other clinicians to better aid women undergoing a TFA in the future.

Materials and Methods

Participants and Recruitment

Individuals who participated in this study were English-speaking women who had undergone a TFA within the last 10 years in the United States and were at least 18 years of age at that time. Participants were recruited through three private online support groups that focused on termination of pregnancy for medical concerns. The moderators of each group approved the survey prior to distribution and posted a prepared invitation to participate in the study, which included a link to access the informed consent, in their respective online communities. Participation in the survey constituted consent, and participants could opt to discontinue at any point in the survey. Participants were recruited from August 2, 2018 through January 7, 2019.

Procedures and Instruments

The Qualtrics (Qualtrics, Provo, UT) software was used to administer the anonymous survey through the UTHealth system to ensure that the survey data was stored on secure UTHealth servers. The survey was separated into three distinct sections. The first portion of the survey included questions about demographics, pregnancy history, perception and experience of coping, and if the participant had seen a genetic counselor to discuss the anomaly found in her pregnancy prior to the TFA.

The second portion included two validated questionnaires, the *brief COPE* survey and the short version of the *perinatal grief scale.* The *brief COPE* survey is a 28-question tool used to assess which of 14 different coping mechanisms (active coping, planning, positive reframing, acceptance, humor, religion, using emotional support, using instrumental support, self-distraction, denial, venting, substance use, behavioral disengagement, and self-blame) are utilized by the participant under a specific stressor using a four-point Likert scale (Carver, 1997). A higher score for a particular coping mechanism indicates greater utilization of that mechanism. The short version of the *perinatal grief scale* (PGS) is a 33-question tool used to assess the level of grief a participant is experiencing following perinatal loss using a five-point Likert scale. Though an overall grief score is given, the scale further groups questions into three progressive levels of grief: active grief, difficultly coping, and despair. The active grief subcategory aims to assess individuals experiencing typical expressions of grief such as crying and being upset about the loss. The difficulty coping subcategory aims to identify if the individual is having trouble adapting back to daily tasks and interacting with loved ones. The despair subcategory aims to identify possible serious and lasting concerns resulting from perinatal loss, such as blaming one's self and feeling guilty about the loss. A higher score indicates more grief in that area or overall (Potvin et al., 1989; Toedter, 2001).

In the final portion of the survey, participants were routed to one of two different question sets dependent on if they had seen a genetic counselor prior to the TFA to discuss the anomaly. The question set for individuals who did not see a genetic counselor included open ended questions about why they chose to decline a genetic counseling consult if they were offered one, if they would like to see a genetic

counselor in the future, the perception of how helpful a genetic counseling consult would have been, and their experience with their non-genetic counselor healthcare provider. The question set for individuals who saw a genetic counselor included open ended questions about the reason they accepted a genetic counseling consult, roles that the genetic counselor fulfilled, expectations for genetic counselors in future pregnancies, their perception of how the genetic counseling consult impacted how they coped post-procedure, and their overall experience with their genetic counselor.

Data Analysis

Quantitative data was analyzed using the Stata (v. 13, College Station, TX) software available through the University of Texas Health Science Center at Houston. Normally distributed continuous data points were described using mean and standard deviation. Non-normally distributed data points were described using median and interquartile ranges. Both validated surveys were scored using the respective analysis tools. *Perinatal grief scale* scores were compared between pertinent groups by means of two tailed t-test statistical analysis due to normal score distribution. *Brief COPE* scores were compared between pertinent groups using Wilcoxon rank-sum statistical analysis due to non-normal score distribution. A p-value of $p < 0.05$ was used to assume statistical significance. Free response questions were thematically coded by the primary investigator and compared by a secondary investigator. The coding was discussed in detail and agreed upon by the two investigators for consistency and validity.

Ethical Considerations

Although participation in this study was not expected to be harmful to participants, steps were taken to recognize the sensitivity of the subject matter. The primary investigator's email was provided in the letter of consent in order for participants to voice any questions or concerns. Participants were also able to voice concerns through the support group moderator to maintain anonymity. Contact information for Mental Health America was also included in the letter of consent as a precaution for any possible emotional stress. We were not made aware of any emotional reactions caused by participation in this study and therefore presume that no respondents experienced major negative responses. Human subjects

approval was obtained through the University of Texas Health Science Center Institutional Review Board (Approval #HSCMS-18-0548).

Results

Participant Demographics

A total of 138 surveys were completed. Of these responses, only the ones who completed at least both of the validated surveys were included in the final analysis. Additionally, participants who indicated that they were unsure if they had seen a genetic counselor prior to undergoing a TFA were excluded. Therefore, the final sample size for analysis was 124 responses (Figure 1).

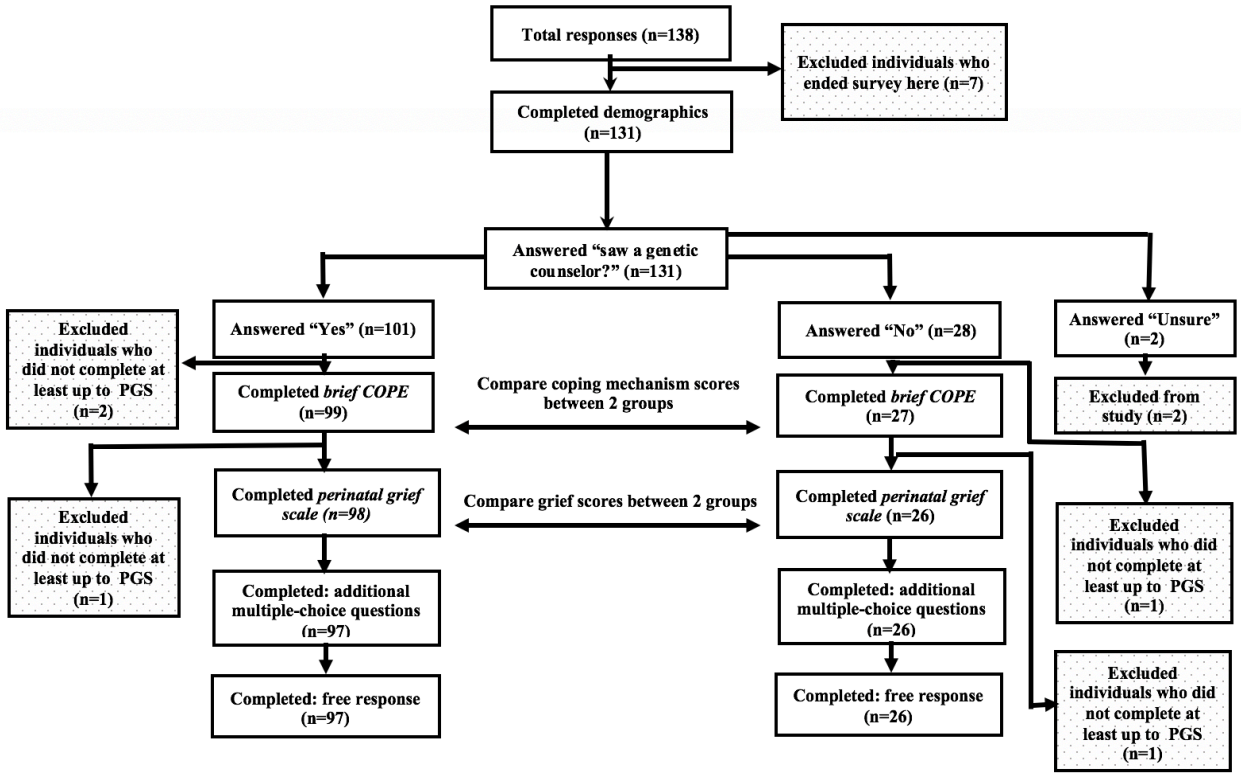


Figure 1: Flowchart of Study Survey and Participation

All respondents underwent a TFA between the ages of 24 – 44 years with a median age of 33 years (IQR 30 -37). Overwhelmingly, respondents identified as Non-Hispanic White (108/124, 87%), followed by Hispanic (6/124, 5%) and Multiracial (4/124, 3%). The most common religious affiliations were Christian (32/124, 26%), Catholic (31/124, 25%) and no religious affiliation (21/124, 17%). All

respondents had completed at least high school or a GED with the majority (110/124, 89%) having at least a bachelor degree (Table 1).

	Total (n =124)		Saw a GC (n =98)		Did not see a GC (n=26)	
	Number of women	**Percentage**	**Number of women**	**Percentage**	**Number of women**	**Percentage**
Age, years						
24-34	71	57%	52	53%	19	73%
35-44	53	43%	46	47%	7	27%
Median	33	IQR 30-37	34	IQR 30-37	32	IQR 29-35
Range	24-44		24 - 44		25 -41	
Race/ethnicity						
Asian	2	2%	2	2%	0	0%
Hispanic/Latina	6	5%	4	4%	2	8%
Non-Hispanic White	108	87%	86	88%	22	85%
Asian Indian	2	2%	2	2%	0	0%
Multiracial	4	3%	3	3%	1	4%
Other	2	2%	1	1%	1	4%
Highest Education						
At least high school/GED	13	10%	9	9%	4	15%
At least Bachelor degree	55	44%	42	43%	13	50%
At least postgraduate degree	55	44%	46	47%	9	35%
Other	1	1%	1	1%	0	0%
Marital Status						
Single	2	2%	0	0%	2	8%
Dating	9	7%	8	8%	1	4%
Common law marriage	4	3%	4	4%	0	0%
Married	108	87%	85	87%	23	88%
Not reported	1	1%	1	1%	0	0%

Table 1: Participant Demographics

A majority of respondents had undergone the TFA less than one year ago (73/124, 59%) while they were in the second trimester of pregnancy (112/124, 91%). Most women did not have other living children at the time of the TFA (66/124, 53%), though 16 out of these 66 respondents (24%) reported at least one

miscarriage or termination of pregnancy prior to the TFA. In addition, a majority of women have not had living children since undergoing the TFA (94/124, 76%) (Table 2).

A majority of respondents reported that the decision to end the pregnancy was at least somewhat difficult (111/124, 90%). Given a ten-point scale (zero being very poor, and ten being very well), most respondents perceived themselves as coping with their grief in a manner between "well" and "poor" (mean 5.7 ±1.88). The perception of how they were dealing with their grief among patients who had a TFA less than two years ago was significantly lower than for patients who had a TFA two or more years ago (median: 5, IQR:4-7 vs median: 7, IQR:6-7, respectively; p=0.001). A similar trend showing improvement in women's perception of how they were dealing with grief over time was observed for women who reported seeing a genetic counselor (p=0.001). In contrast, there was no significant difference (p=0.257) in the perception of dealing with grief over time among women who did not see a genetic counselor. However, it should be noted that this latter group only had five respondents.

	Total (n =124)		Saw a GC (n =98)		Did not see a GC (n=26)	
	Number of women	**Percentage**	**Number of women**	**Percentage**	**Number of women**	**Percentage**
Time Since TFA						
Less than 1 year	73	59%	54	55%	19	73%
1 year to less than 2 years	19	15%	17	17%	2	8%
2 or more years	32	26%	27	28%	5	19%
Trimester at TFA						
1st trimester (1-13 weeks)	10	8%	9	9%	1	4%
2nd trimester (14-27 weeks)	112	91%	87	89%	25	96%
3rd trimester (28 or more weeks)	1	1%	1	1%	0	0%
Living Children at time of TFA						
Yes	58	47%	47	48%	11	42%
No	66	53%	51	52%	15	58%
Living children since TFA						
Yes	30	24%	24	24%	6	23%
No	94	76%	74	76%	20	77%

Table 2: Participant Pregnancy Information

The most common anomaly discovered among the study population was a chromosome disorder including Down syndrome, trisomy 13, trisomy 18, monosomy X, or another chromosome abnormality (85/124, 69%). Anomalies involving the fetal brain and/or the fetal heart were also common (29/124, 23%). It should be noted that 18 out of 124 participants selected more than one anomaly. Regardless, many respondents (54/124, 44%) reported that they were told the condition would not be viable. Participants were able to select multiple potential prognoses and other options commonly selected included intellectual disability and physical impairment. Of our respondents, seven reported that they were not told anything about the anomaly and one reported that she was unable to remember what she was told. Of note, 35 individuals selected more than one prognosis, however, if they indicated that the pregnancy would not survive, they were only counted in that category (Figure 2).

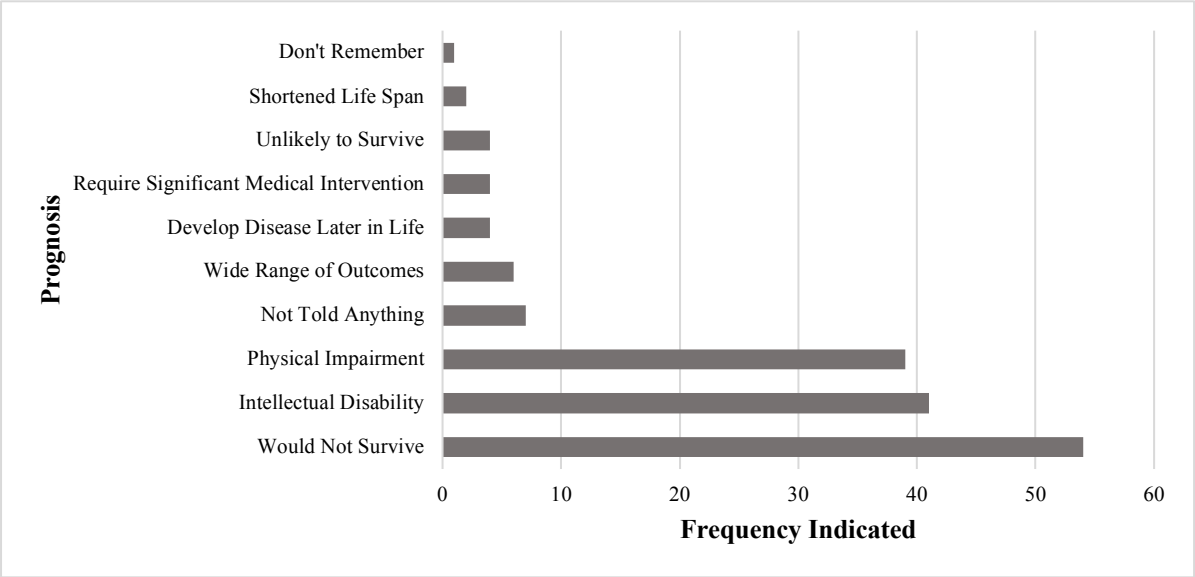


Figure 2: Prognosis of Anomaly Discovered in Pregnancy

Factors Influencing Coping

The most commonly identified factor as having the most positive impact on coping was their partner, followed by support groups, and then their family and friends. In comparison, the most commonly identified factor as having the most negative impact on coping was family and friends followed by religious/spiritual faith (Figure 3). Of note, recurrent themes identified from those who indicated "other" as most negatively impacting coping included their work environment, judgement felt from society, the current political climate and seeing healthy pregnancies.

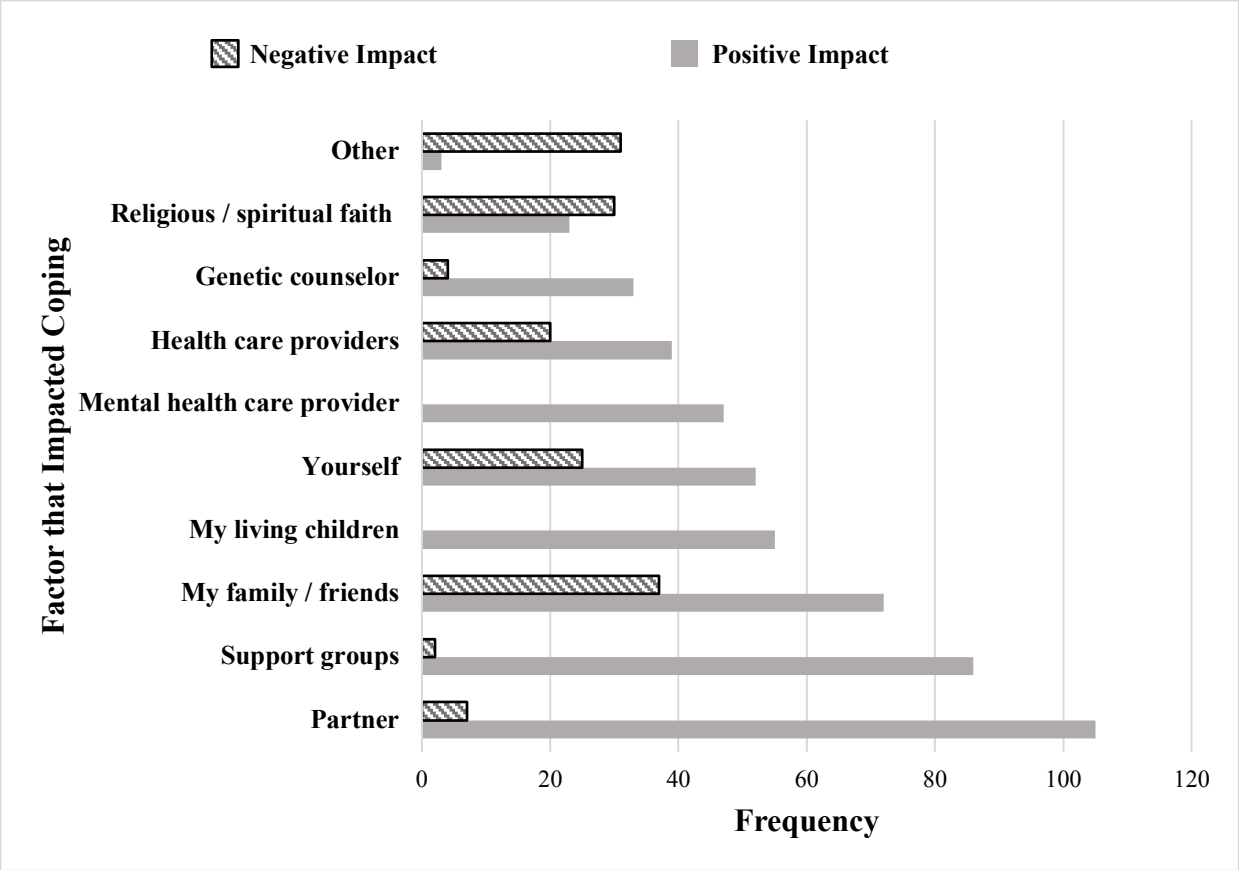


Figure 3: Factors Women Identified as Impacting Coping

Perinatal Grief Scale and Brief COPE

There was no significant difference in the short version of the *perinatal grief scale* scores between individuals who saw a genetic counselor and those who did not for any of the subcategories or in total scores. There was also no significant difference when stratifying the groups further by time since undergoing the TFA. There was a significant difference in all subcategories of the *perinatal grief scale* scores between individuals who saw a genetic counselor and underwent a TFA less than two years ago compared to those who saw a genetic counselor and underwent a TFA more than two years ago. Interestingly, there was no significant difference in participant grief scores for those that did not see a GC, even when stratified by time (Figure 4).

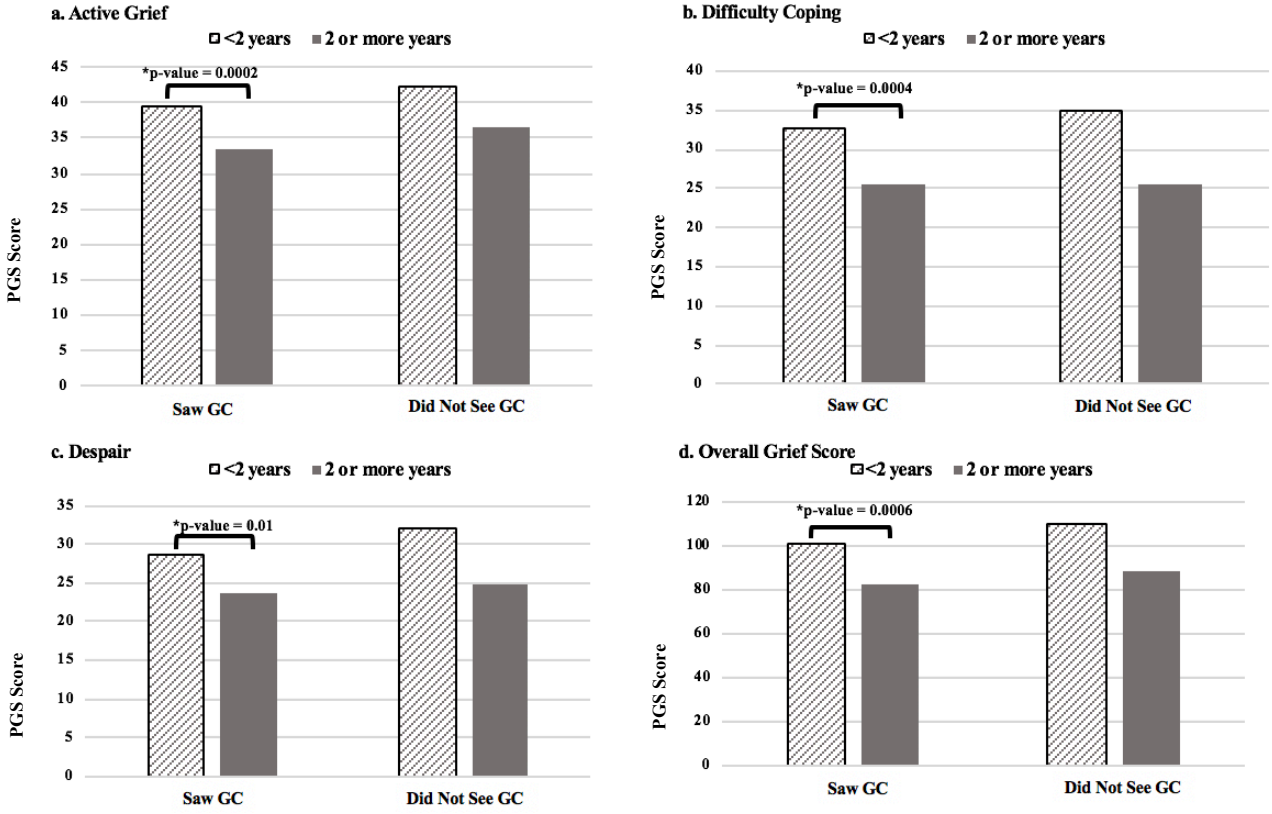


Figure 4 a-d: Comparing Perinatal Grief Scale Scores Across Time (<2 years since TFA, 2 or more years since TFA) Within Groups of Women who saw a Genetic Counselor and Those Who Did Not See a Genetic Counselor. Figure a: Active grief subscale of the perinatal grief scale. Figure b: Difficultly coping subscale of the perinatal grief scale. Figure c: Despair subscale of the perinatal grief scale. Figure d: Overall grief scores from the perinatal grief scale.

Individuals who saw a genetic counselor had significantly higher active coping scores on the brief COPE validated survey than individuals who did not see a genetic counselor (median: 6, IQR:5-7 vs median: 4.5, IQR:4-6, respectively; p=0.002). When the two groups were further stratified by time, individuals who underwent a TFA less than 2 years ago and who saw a genetic counselor had significantly higher active coping (median: 6, IQR:5-7 vs median: 4, IQR:4-5, respectively; p=0.001), positive reframing (median: 4, IQR:3-6 vs median: 3, IQR:2-4, respectively; p=0.03), and planning scores (median: 6, IQR:4-7 vs median: 5, IQR:4-6, respectively; p=0.03). For individuals who underwent a TFA more than two years ago, those who saw a genetic counselor were also significantly less likely to utilize humor compared to those who did not see a genetic counselor (median: 2, IQR:2-2 vs median: 2, IQR:2-3,

respectively; p=0.02) (Table 3).

	All Respondents			Time since TFA <2 years			Time since TFA 2 or more years		
	Have Seen GC Median Score (IQR)	Have Not Seen GC Median Score (IQR)	P-value	Have Seen GC Median Score (IQR)	Have Not Seen GC Median Score (IQR)	P-value	Have Seen GC Median Score (IQR)	Have Not Seen GC Median Score (IQR)	P-value
Self-Distraction	6 (4 - 7)	6 (5 - 7)	0.820	6(4-7)	6(5-7)	0.816	5(4-6)	5(5-6)	0.492
Active Coping	6 (5 - 7)	4.5 (4 - 6)	**0.002***	6(5-7)	4(4-5)	**0.001***	6(4-7)	5(5-6)	0.937
Denial	2 (2 - 3)	2 (2 - 5)	0.099	2(2-3)	3(2-5)	0.099	2(2-3)	2(2-2)	0.918
Substance Use	2 (2 - 2)	2 (2 - 4)	0.064	2(2-2)	2(2-4)	0.226	2(2-2)	3(2-4)	0.087
Emotional Support	6 (5 - 8)	6 (4 - 7)	0.402	6(5-8)	6(4-7)	0.309	6(5-8)	7(6-7)	0.790
Instrumental Support	5 (4 - 6)	5 (3 - 6)	0.683	5(4-7)	5(3-6)	0.284	5(4-6)	7(5-7)	0.186
Behavioral Disengagement	2 (2 - 4)	3 (2 - 4)	0.062	2(2-4)	3(2-4)	0.066	2(2-3)	2(2-3)	0.768
Venting	4 (4 - 6)	5 (3 - 6)	0.559	5(4-6)	5(3-6)	0.973	4(3-5)	5(4-5)	0.283
Positive Reframing	4 (3 - 6)	3 (2 - 4)	0.066	4(3-6)	3(2-4)	**0.031***	4(3-6)	5(4-5)	0.813
Planning	5.5 (4 - 7)	4.5 (4 - 6)	0.053	6(4-7)	5(4-6)	**0.027***	4(3-6)	4(4-5)	0.895
Humor	2 (2 - 2)	2 (2 - 2)	0.672	2(2-3)	2(2-2)	0.154	2(2-2)	2(2-3)	**0.016***
Acceptance	7 (6 - 8)	6.5 (5 - 8)	0.195	7(6-8)	6(5-8)	0.262	7(6-8)	7(7-7)	0.662
Religion	4 (2 - 5)	4 (2 - 4)	0.837	3(2-4)	4(2-4)	0.656	4(3-5)	4(4-4)	0.873
Self-Blame	4 (2 - 5)	4 (2 - 6)	0.626	4(3-6)	5(3-6)	0.540	4(2-5)	2(2-4)	0.567

Table 3: Median Brief COPE Scores Between Those Who Saw a Genetic Counselor And Those Who Did Not See a Genetic Counselor. *Significant differences are marked in bold with an asterisk.*

Reports From Women Who Did Not See a Genetic Counselor

Of the 26 participants that did not see a genetic counselor prior to their TFA, 54% (14/26) reported that genetic counseling was not offered. Of the 10 (10/26, 38%) participants that actively declined genetic counseling, the main reasons reported were that they felt they had enough information from their healthcare provider (4/10, 40%), appointment times were not available (2/10, 20%), and that they did not want to see a genetic counselor (2/10, 20%). However, of all of those who did not see a genetic counselor, 48% (12/25) indicted that they believed seeing a genetic counselor would have been helpful or extremely helpful. Most (18/26, 69%) indicated that they would want to or at least might want to see a genetic counselor in future pregnancies with an additional 12% (3/26) reporting that they had already seen a genetic counselor in another pregnancy.

Reports From Women Who Saw a Genetic Counselor

Among the 98 women who did report seeing a genetic counselor prior to their TFA, 97 completed questions about their experience with their genetic counselor. Of these 97 women, 83 (83/97, 86%) participants reported that a reason they accepted the appointment was the referral from their physician(s). Though 15/97 (15%) chose this as the only reason for accepting the genetic counseling appointment, participants were able to select more than one answer. Other commonly selected reasons included that they wanted more information about recurrence risk (66/97, 68%), they wanted more information about the abnormality found in the pregnancy (64/97, 66%) and they wanted more information about genetic testing (63/97, 65%). When asked what roles the genetic counselor fulfilled during the session, the most commonly reported were that the genetic counselor gave information about genetic testing (86/97, 89%), explained and gave information about the abnormality found in the pregnancy (84/97, 87%), discussed recurrence risks (81/97, 84%), and organized genetic testing (76/97, 78%). The least common roles reported were the genetic counselor discussed expectations following the termination (28/97, 29%) and discussed expectations of the termination (38/97, 39%). Of these women, 37 (37/97, 38%) indicated that there was at least one role that they would have liked their genetic counselor to have provided that they did not. When asked what these roles were, they reported wanting more compassionate care and emotional support (12/37, 32%), more information (16/37, 43%), follow up care including coordination of the procedure and referrals (14/37, 38%), and support resources (14/37, 38%).

Of those who saw a genetic counselor, 47% (46/97) indicated they would want to see a genetic counselor in future pregnancies with an additional 13% (12/97) reporting they have seen a genetic counselor in another pregnancy following the TFA. The most commonly reported expectations for genetic counselors in future pregnancies included organizing genetic testing, providing information about genetic testing, and reviewing recurrence risk (Figure 5).

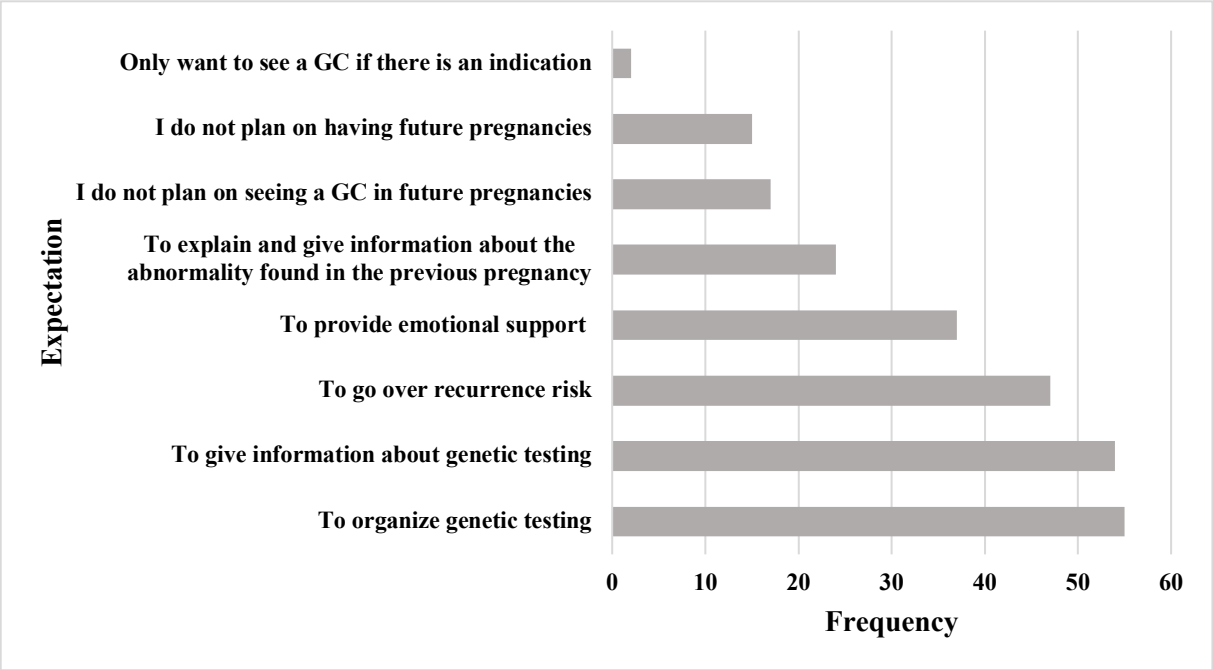


Figure 5: Expectations of Genetic Counselors in Future Pregnancies

Experiences with Healthcare Providers and Impact on Coping

In the free responses of participants who did and did not see a genetic counselor prior to their TFA, similar factors that led to positive or negative experiences were identified. When reviewing these responses, three common themes emerged: importance of follow up care, the value of compassionate care, and the desire for information from their provider. The information desired ranged from details about the diagnosis, including prognosis, expected quality of life, and recurrence risk, to expectations of the termination procedure, such as timeline and potential decisions regarding the remains.

Free response questions regarding the reason participants would like to see a genetic counselor in the future revealed two commonalities between those who would like to see a genetic counselor and those who would not. Both groups cited their past experience with a genetic counselor as influencing their desire to see one in the future. In addition, many individuals in both groups reported they would only want to see a genetic counselor if there was an indication in their pregnancy. Of only those who indicated wanting to see a genetic counselor in future pregnancies, two major themes arose: desire for

genetic testing and emotional support. On the other hand, the major theme identified as a reason participants would not want to see a genetic counselor in future pregnancies is feeling they do not need more information about the anomaly in their last pregnancy.

When asked if they felt their genetic counselor impacted their ability to cope post-TFA, 55% (53/97) of women reported the genetic counselor had a positive impact, 6% (6/97) reported a negative impact, and 39% (38/97) reported no impact or that they were unsure if the genetic counselor had an impact on their coping. Several roles were identified as the reasons that women perceived their genetic counselor as having a positive impact on their ability to cope, notably they felt their genetic counselor provided objective care and emotional support, provided information, follow-up care, and support resources (Table 4). The importance of objective care and emotional support as well as being provided accurate information and realistic expectations of the prognosis were stressed by respondents as it promoted confidence in decision making:

"She made me feel confident and fully informed on my decision to terminate. Which I believe has helped me heal because I don't look back on my termination and question my decision."

Participants also remarked on the information provided to them, especially recurrence risk, as being a source of hope for future pregnancies and understanding that they were not responsible for the anomaly:

"We knew this would not happen again, and that it was a freak occurrence."

Identified Role Having An Impact (n=70)	**Coded Under This Role**	**Positive**	**Negative**
Objective Care and Emotional Support (n=37)	No judgement, compassionate care, listening to the patient, felt understood, felt GC familiar with situation, assured weren't alone, worked together, advocate for patient, support through process, time and attention to care	*"She was a friend to me and listened without judgement"*	*"I felt judged and as if she was trying to sway my opinion/decision towards continuing the pregnancy"*
Information (n=34)	Etiology of diagnosis, realistic about prognosis/results, felt GC knowledgeable, recurrence risk	*"Knowing my baby's future outcome and quality of life was an important deciding factor in my termination"*	*"I didn't get real life examples to understand what the kid would have really dealt with as an adult"*
Follow Up Care (n=22)	Coordination of care, referrals, followed up after initial session/after TFA, available to patient after session	*"I was able to call and talk to someone anytime..."*	*"...but I didn't hear from [the genetic counselor] afterwards"*
Support Resources (n=4)	GC providing resources (support groups, pamphlets, etc.)	*"My genetic counselor met with my husband and I a few weeks prior to termination to check in and discuss joining a support group in which I did"*	*"...[I wasn't provided] anything that would have been useful to me post termination."*

Table 4: Major Roles Provided By A Genetic Counselor That Were Identified As Having An Impact On Coping By Women Who Underwent TFA and Saw A Genetic Counselor. N's refer to the number of comments.

Individuals who reported a negative experience with their genetic counselor cited a lack of one or more of these roles identified as having a positive impact (Table 4). Of the six individuals who specifically reported that their genetic counseling experience had a negative impact on coping, all indicated that there were roles they would have liked their genetic counselor to fill that they did not, specifically in relation to emotional support, follow up, providing more and accurate information, and providing support resources and resources regarding the termination. Interestingly, all of these six women said they would either want to see a genetic counselor in the future or that they might want to, if they indicated they were planning future pregnancies. However, in their reasoning for this response, most seemed to see the session as a requirement for having testing. Individuals who reported no impact or that they were unsure

of the impact of genetic counseling on their coping expressed already knowing the information they desired, not having enough interaction with the genetic counselor, having a strong outside source of grief, and having inconsistent experiences when seeing multiple genetic counselors within the same pregnancy. Some of these experiences were reported as very different, and involved positive experiences with one genetic counselor being overshadowed by negative experiences with another genetic counselor.

Discussion

This study explored patient experiences and their expectations of genetic counselors as they undergo TFA and how they may impact their levels of grief and coping mechanisms. While grief following a TFA can be long-lasting, our study provides evidence that genetic counseling may promote utilization of positive coping mechanisms during the most significant period of grief. Individuals who underwent a TFA less than two years ago and saw a genetic counselor were more likely to use active coping, positive reframing, and planning as compared to women who did not see a genetic counselor. All three of these mechanisms are considered adaptive coping mechanisms, which are generally defined as positive techniques that help to lessen stress.

Even beyond the initial two years following a TFA, women who saw a genetic counselor prior to undergoing a TFA had significantly higher active coping scores. Although we cannot determine causation from our study, we theorize that the use of this specific coping mechanism could be a result of women having greater understanding of the potential grief process following a TFA. As genetic counselors may have more experience with pregnancies with anomalies and pregnancy management decisions, they may be able to provide guidance on the grief process as well as employ active listening and reflection to help patients recognize their own needs and concerns, and to identify individualized steps to lessen these stressors.

Although the *perinatal grief scale* scores were not significantly different between individuals who saw a genetic counselor and those who did not, individuals who saw a genetic counselor had lower average

scores. Despite the difference, both groups qualified as having high levels of grief overall as well as in all subcategories, again emphasizing the considerable amount of grief that may be involved in undergoing a TFA (Toedter et al., 2001). When stratified by time, individuals who did see a genetic counselor had a significant decrease in grief scores at least two years post-TFA. Although the lack of significance in the group who did not see a genetic counselor may be attributed to the small sample size, this suggests time is a significant factor in decreasing grief for those who saw a genetic counselor whereas it is not a significant factor for those that did not see a genetic counselor. Two years is a notable amount of time in which individuals may experience significant life events, including potentially going on to have healthy pregnancies. Thus, we speculate that the positive difference in levels of grief over time is a result of life events in the two year period following a TFA combined with the utilization of positive coping mechanisms, such as positive reframing, that focus on the future.

When specifically asked about the impact of genetic counseling in their coping process, many commented on the importance of compassionate care and were appreciative of the amount of time their genetic counselor spent with them. Respondents expressed that such care made them feel that they had an advocate and that they were not alone through the TFA process. Genetic counselors that provided objective care and emotional support, gave information on etiology and recurrence risks, identified support resources, and made a plan for follow up care were all perceived to have a positive impact. Being provided objective care and emotional support as well as information about the prognosis was noted to play a large role in women feeling confident in their decision-making and to not question their decision in the future. This can be an important factor as doubt while making the decision to terminate is a predictor of negative long-term outcomes (Kersting and Wagner, 2012).

Additionally, being provided information about recurrence risk and etiology of the anomaly found in the pregnancy were specifically listed as important factors in coping post-TFA. Many women reported using this information as a source of hope for future pregnancies as it provided reassurance that the anomaly was not their fault. The significance of information about etiology and the positive emotional

impact reported in our study has been shown in previous research that identified self-blame as a factor that potentially prolongs grief; individuals were shown to demonstrate relief after understanding that they were not responsible for the anomaly in their pregnancy (Kersting and Wagner, 2012; Maguire et al., 2015).

Interestingly, respondents who noted a negative experience with their genetic counselor(s), cited a lack of one or more of these key roles. The relationship between the factors women identified as having positive impacts on coping and the factors identified as having a negative impact suggest that they are among some of the most important roles for genetic counselors to provide to individuals in order to promote a positive impact on coping.

Women also cited their experience with the previous genetic counselor as influential on their desire to see one in the future, regardless if this was a positive or negative experience. That being said, most women who reported planning to have a future pregnancy wanted to see a genetic counselor. The most common expected roles for a genetic counselor to fill involved coordinating genetic testing and reviewing recurrence risk as well as providing emotional support and giving information about the anomaly in the previous pregnancy. However, several participants remarked that they would only want to see a genetic counselor if there was an indication in the pregnancy. Though some may want to distance themselves from the events of the prior pregnancy, we wonder if there may be a misconception on the scope of practice of a genetic counselor and that women may associate a genetic counseling session with only negative circumstances rather than the possibility of providing care and emotional support in a healthy, future pregnancy. As this previous experience weighs on a woman even in future pregnancies, it is important for genetic counselors to elicit the patient's perception of her previous care and what she would desire from the current session to help lessen any anxieties. This discussion of patient expectations may be powerful in setting a mutual agenda and providing patient centered care.

Another important exploration in this study are the reasons that women accepted their appointment with their genetic counselor. Many reported personal motivations for wanting more information about genetic testing, recurrence risk, and the anomaly found in their pregnancy. However, a subset of respondents reported that the physician referral was the sole reason for accepting the genetic counseling appointment. This highlights the role of the referring physician in offering genetic counseling after an anomaly is identified and the need for increased education about the scope of genetic counseling. Several respondents in our study noted not seeing a genetic counselor as they were told the anomaly was not genetic. In reviewing the indications of these respondents, there were reports of trisomy 13 and anencephaly. Though these indications are likely to not be inherited, some are a result of genetic changes and associated with increased recurrence risks. As our study shows, accurate information about etiology and recurrence risk are desired by this patient population and may help alleviate self-blame. Thus, genetic counseling for conditions or anomalies that are deemed sporadic can still be of benefit to patient care and coping.

Study Strengths and Limitations

Strengths of our study included quantitative data supplemented by qualitative free response which not only identified significant difference in between populations but explored these differences from the perspective of women who underwent a TFA. The fairly large study population of individuals who saw a genetic counselor strengthened our qualitative analysis in allowing us to identify several recurrent themes. In addition, the use of two validated tools strengthened our conclusions made about grief and coping mechanisms used.

Limitations of our study include the study population itself as support groups are comprised of a select group of individuals that have self-identified as needing support and who are actively seeking support. Many women in our study identified support groups and other support resources as being one of the factors that most positively impacted their ability to cope. While support groups have been shown to be positive resources for individuals in many circumstances (Turner, 2017), we are aware that our study

population may constitute a biased population of women who have benefited from such resources. As the support groups we recruited from are private, we were unable to calculate a response rate. Thus, there is a lack of detailed information on those who had an opportunity to participate but ultimately declined participation in the study. This may have caused a further selection bias as the grief scores and coping mechanisms for individuals who declined participation may be different than those who participated. Additionally, those needing support but not actively seeking out support would have not had an opportunity to participate.

Additionally, our study population largely consisted of highly-educated, Caucasian individuals. This is consistent with the overall observed demographics in most online support groups and in most previous studies exploring TFA (Gold, 2016; Gold, 2011; Lafarge et al., 2013; Ramdaney et al., 2015). Though our study population may not be representative of all women electing TFA, it is likely that individuals who have greater financial resources and better access to care may be a large portion of this population due to cost and time constraints surrounding the termination procedure.

Future Directions

While this study was able to demonstrate a positive impact of genetic counselors on the coping mechanisms utilized by women following TFA and identify important aspects of care, the sample size limited the power on some comparisons and therefore did not allow us to explore all significant differences in coping between those who saw a genetic counselor and those who did not. Therefore, we call for a larger study with a more generalizable population to be completed in order to determine if these results can be extrapolated to the broader patient population seen by genetic counselors, including those who are non-Caucasian and not involved in support groups. In addition, given that this study was able to identify key aspects of care associated with a positive impact on coping, further research looking closer at these factors in a prospective manner is needed to help attribute causation to the associations seen in our study.

Future research is also needed to evaluate current educational standards in Genetic Counseling Training Programs in TFA-related topics. Although the desired roles indicated by the respondents in our study are all included in the genetic counseling scope of practice published by the Accreditation Council for Genetic Counseling (ACGC) (ACGC, 2013), there is no specific mention of exposure to or education on counseling women undergoing termination of pregnancy as part of the ACGC Standards of Accreditation for Graduate Programs in Genetic Counseling (ACGC, 2019). As such, genetic counselors may have different perceptions of what women undergoing a TFA may find beneficial and lead to inconsistencies in care. Several respondents in our study noted seeing multiple providers, including multiple genetic counselors, and that the experiences and their impact varied significantly. Some of these differences were noted to be so polar that it caused a woman who had a positive experience with one provider to have an overall negative or neutral experience due to interactions with another. Though individual care may differ based on the specific needs of the patient, our study suggests that more focus in training programs to provide genetic counseling students with education on the topic and on the needs of women undergoing a TFA may be beneficial in promoting a more universal practice.

Conclusions

This study creates understanding of the expectations and needs of women going through a TFA as well as those with a history of a TFA. Genetic counselors can be an important part of the healthcare team for these women as they possess a unique skill set designed to provide key clinical and emotional care, which have the potential to positively impact the coping process post-TFA. Our study was able to identify key roles for genetic counselors that may have the most impact, specifically providing emotional support and objective care, explaining information about the etiology and prognosis of the anomaly, identifying support resources, and offering follow-up care. Responses even suggest that not providing these roles may negatively impact coping post-procedure. We believe that the findings of this study are vital to clinical practice in order to benefit care for women in these circumstances. However, there is still

need for increased education and awareness of TFA-related care within genetic counseling practice as well as the overall healthcare community.

Appendix A: Online Support Group Post

Hi everyone,

My name is Cayleen Smith and I am a graduate student at the University of Texas Health Sciences Center at Houston. For my thesis project, I am conducting a research study on the impact that seeing or not seeing a prenatal genetic counselor has on a woman's ability to cope after undergoing termination for fetal anomaly and the expectations that women have for genetic counselors in such circumstances. We welcome both women who have seen a genetic counselor and those who have not, as we aim to learn about the different healthcare experiences women have in these circumstances and how they compare to experiences with genetic counselors. We feel that this information will be important in helping healthcare providers better understand how to aid women going through this difficult process and could potentially lead to future changes in healthcare practices.

I would like to invite you take part in this study by completing the following survey. To be eligible to participate, you must have undergone termination for fetal anomaly, in the United States, in the past 10 years and were 18 years or older at the time. You do not have to have seen a genetic counselor to participate.

The survey is anonymous and will take approximately 15 to 20 minutes to complete.

If you would like to take part in the study or for more information, please go to https://uthtmc.az1.qualtrics.com/jfe/form/SV_3DcY31NisxiRAEd.

If you are a member of another online support group for women who have had a termination of pregnancy for fetal anomaly and think that others in that group may be open to participating in this survey, please email me at the email address listed below. I would love to reach out to as many women as possible.

Thank you for your interest in my project.

Sincerely,

Cayleen Smith
Contact email address: cayleen.smith@uth.tmc.edu

Appendix B: Letter of Invitation

INFORMED CONSENT FORM TO TAKE PART IN RESEARCH
Title: Termination for Fetal Anomaly: What is the Impact of Genetic Counseling on Coping?
Letter of Information
(HSC-MS-18-0548)

Dear Potential Participant,

My name is Cayleen Smith and I am a graduate student at the University of Texas Health Sciences Center at Houston. For my thesis project, I am conducting a research study on the impact that seeing a genetic counselor has on a woman's ability to cope after undergoing termination for fetal anomaly and the expectations that women have for genetic counselors in such circumstances. This information will be important in helping healthcare providers better understand how to aid women going through this difficult process and could potentially lead to future changes in healthcare practices to better fit the needs of these women.

I would like to invite you take part in this study by completing the following survey. To be eligible to participate, you must have undergone termination for fetal anomaly, in the United States, in the past 10 years and were 18 years or older at the time.

The survey will take approximately 15 to 20 minutes to complete. If you choose to participate, please answer the questions honestly and to the best of your ability. The questions will include a brief demographic section followed by questions regarding your experience with grief and coping post procedure. The survey will conclude with questions about your personal experience with genetic counselors or other health care providers.

Participation in this study is voluntary. You may skip any questions you do not wish to answer. A decision not to take part in this study will not change any services you are currently receiving.

This study is anonymous. This information collected will not contain identifying information. You will not be personally identified in any reports or publications that may result from this study. There is a possible risk of a breach of confidentiality; however, any personal information about you that is gathered during this study will remain confidential to every extent of the law.

There is no cost and you will not be paid to take part in this study.

You may not receive any benefit from taking part in this study. However, the information you provide will help us better understand the needs and expectations of women going through termination for fetal anomaly to potentially lead to future changes in health care practices.

There are no known risks to take part in this study. We recognize that this topic as well as some of the questions within the survey may be sensitive. If you feel that you are struggling with coping or grief, you may consider visiting www.mentalhealthamerica.net for more information about support groups, referrals to professional services and a 24-hour crisis hotline. You have the alternative to choose to not take part in this study and can withdraw at any time.

In order to begin the survey please press the arrow at the bottom right of your screen. Continuing with the survey will serve as your informed consent. Thank you again for your participation.

Sincerely, Cayleen Smith

Contact email address: cayleen.smith@uth.tmc.edu

CPHS Statement: This research project has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Health Science Center at Houston (HSC- MS-18-0548). For any questions about research subject's rights call CPHS at (713) 500-7943.

Thank you for your interest in my research study. If you would like any additional information or have other questions or concerns, please feel free to contact me at the email address listed below.

IRB NUMBER: HSC-MS-18-0548 IRB APPROVAL DATE: 07/30/2018

UTHealth
The University of Texas

Appendix C: Study Survey

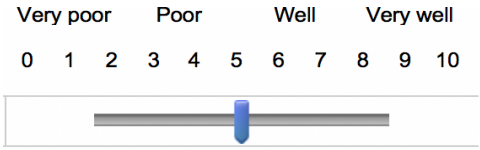
1. Have you had a termination of pregnancy because of a fetal anomaly? This includes birth defects, genetic conditions, chromosome abnormalities, etc. This does not include maternal health concerns such as maternal diabetes, maternal blood pressure, etc.
    a. Yes, once
    b. Yes, more than once
    c. No
2. How old were you when you underwent termination of pregnancy?
    a. Drop down menu, 18 years old-45 and older
3. How much time has passed since your termination of pregnancy?
    a. Less than 1 year
    b. 1 year to less than 2 years
    c. 2 years to less than 3 years
    d. 3 years to less than 4 years
    e. 4 years to less than 5 years
    f. 5 years to less than 6 years
    g. 6 years to less than 7 years
    h. 7 years to less than 8 years
    i. 8 years to less than 9 years
    j. 9 years to 10 years
    k. More than 10 years
4. What state were you living in at the time of your termination of pregnancy?
    a. Drop down menu with all states listed, including the options of "I was living in the United States but prefer not to indicate the specific state" and "I was not living in the United States"
5. What is your race/ethnicity?
    a. African American
    b. American Indian
    c. Asian
    d. Hispanic or Latina
    e. Non-Hispanic White
    f. Asian Indian
    g. Multiracial
    h. Other
6. What was your marital status at the time of termination?
    a. Single
    b. Dating
    c. Married
    d. Common Law Marriage
    e. Divorced
    f. Widowed
    g. Separated
    h. Prefer not to answer
7. What was your religion at the time of termination?
    a. Christian
    b. Catholic
    c. Jewish
    d. Muslim
    e. Hindu

f. Buddhist
g. Atheist
h. Agnostic
i. Other
j. No religious affiliation
k. Prefer not to answer

8. What is your highest level of education completed?
    a. Elementary or middle school
    b. Some high school
    c. High school graduate/GED
    d. Some college
    e. Trade/tech/vocational
    f. College graduate/bachelor degree
    g. Some postgraduate work
    h. Postgraduate degree/masters/doctorate
    i. Other
9. At the time of the termination, including that pregnancy, how many times had you been pregnant?
    a. 1
    b. 2
    c. 3
    d. 4 or more
10. How many living children did you have at that time?
    a. 0
    b. 1
    c. 2
    d. 3 or more
11. How many living children have you had since the termination?
    a. 0
    b. 1
    c. 2
    d. 3 or more
12. What kind of abnormality was discovered? Check all that apply.
    a. Brain
    b. Head
    c. Face
    d. Heart
    e. Chest
    f. Spine
    g. Limb
    h. Down Syndrome/Trisomy 21
    i. Trisomy 18
    j. Trisomy 13
    k. Turner Syndrome/monosomy X/45, X
    l. Other chromosome abnormality
    m. I don't know/remember
    n. Other (please describe): _____
13. What were you told about the anomaly discovered? Check all that apply.
    a. Fetus/infant would not survive
    b. Infant would have physical impairment
    c. Infant would have intellectual/mental impairment
    d. Infant would develop disease later in life

e. Cannot remember what I was told about anomaly discovered
f. Was not told anything about anomaly discovered
g. Other (please describe): _____

14. How far along in the pregnancy were you at the time of termination of pregnancy?
    a. First trimester (1-13 weeks)
    b. Second trimester (14-27weeks)
    c. Third trimester (28 or more weeks)
15. How hard was the decision to end the pregnancy?
    a. Extremely
    b. Moderately
    c. Somewhat
    d. Not difficult
16. On a scale of 1-10, how do you feel that you have been dealing with your grief?



17. What do you feel has most positively impacted your ability to cope? Check all that apply
    a. My partner
    b. My family/friends
    c. My living children
    d. Religious/spiritual faith
    e. Health care providers
    f. Genetic counselor
    g. Mental health care provider
    h. Support groups
    i. Yourself
    j. Other, please explain: _____
    k. None of the above
18. What do you feel has most negatively impacted your ability to cope? Check all that apply
    a. My partner
    b. My family/friends
    c. My living children
    d. Religious/spiritual faith
    e. Health care providers
    f. Genetic counselor
    g. Mental health care provider
    h. Support groups
    i. Yourself
    j. Other, please explain: _____
    k. None of the above

Genetic counselors have specialized education in genetics and counseling to provide personalized help patients may need as they make decisions about their genetic health. Genetic counselors have advanced training in medical genetics and counseling to interpret genetic test results, and to guide and support patients seeking more information about such things as:

- How inherited diseases and conditions might affect them or their families.
- How family and medical histories may impact the chance of disease happening again in future pregnancies.
- Which genetic tests may or may not be right for them, and what those tests may or may not tell.

- How to make the most informed choices about healthcare conditions.

19. Did you see a genetic counselor to discuss the anomaly found in your pregnancy before you had the termination?
    a. Yes
    b. No
    c. Unsure

20. Have you ever seen a genetic counselor for another reason?
    a. Yes, for other pregnancy-related care
    b. Yes, for non-pregnancy related care (ex. cancer genetic counseling)
    c. No
    d. Unsure

The next set questions are part of a validated survey used to assess the type of coping mechanism that a person is using to deal with a specific situation. Please indicate how often you **currently** do the following statements. Don't answer on the basis of whether it seems to be working or not - just whether or not you're doing it. Try to rate each item separately in your mind from the others.

	I haven't been doing this at all	**I've been doing this a little bit**	**I've been doing this a medium amount**	**I've been doing this a lot**
1. I've been turning to work or other activities to take my mind off things.	1	2	3	4
2. I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
3. I've been saying to myself "this isn't real".	1	2	3	4
4. I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
5. I've been getting emotional support from others.	1	2	3	4
6. I've been giving up trying to deal with it.	1	2	3	4
7. I've been taking action to try to make the situation better.	1	2	3	4
8. I've been refusing to believe that it has happened.	1	2	3	4
9. I've been saying things to let my unpleasant feelings escape.	1	2	3	4

10. I've been getting help and advice from other people.	1	2	3	4
11. I've been using alcohol or other drugs to help me get through it.	1	2	3	4
12. I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
13. I've been criticizing myself.	1	2	3	4
14. I've been trying to come up with a strategy about what to do.	1	2	3	4
15. I've been getting comfort and understanding from someone.	1	2	3	4
16. I've been giving up the attempt to cope.	1	2	3	4
17. I've been looking for something good in what is happening.	1	2	3	4
18. I've been making jokes about it.	1	2	3	4
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
20. I've been accepting the reality of the fact that it has happened.	1	2	3	4
21. I've been expressing my negative feelings.	1	2	3	4
22. I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
23. I've been trying to get advice or help from other people about what to do.	1	2	3	4
24. I've been learning to live with it.	1	2	3	4
25. I've been thinking hard about what steps to take.	1	2	3	4

26. I've been blaming myself for things that happened.	1	2	3	4
27. I've been praying or meditating.	1	2	3	4
28. I've been making fun of the situation.	1	2	3	4

The next set of questions are part of a validated survey to assess levels of grief in women after experiencing a prenatal loss. Please indicate how much you agree or disagree with the following statements at this **current** time.

Statement	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. I feel depressed	1	2	3	4	5
2. I find it hard to get along with certain people	1	2	3	4	5
3. I feel empty inside	1	2	3	4	5
4. I can't keep up with my normal activities	1	2	3	4	5
5. I feel a need to talk about the baby	1	2	3	4	5
6. I am grieving for the baby	1	2	3	4	5
7. I am frightened	1	2	3	4	5
8. I have considered suicide since the loss	1	2	3	4	5
9. I take medicine for my nerves	1	2	3	4	5
10. I very much miss the baby	1	2	3	4	5
11. I feel I have adjusted well to the loss	1	2	3	4	5
12. It is painful to recall memories of the loss	1	2	3	4	5
13. I get upset when I think about the baby	1	2	3	4	5
14. I cry when I think about him / her	1	2	3	4	5

Statement	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
15. I feel guilty when I think about the baby	1	2	3	4	5
16. I feel physically ill when I think about the baby	1	2	3	4	5
17. I feel unprotected in a dangerous world since he/she died	1	2	3	4	5
18. I try to laugh, but nothing seems funny anymore	1	2	3	4	5
19. Time passes so slowly since the baby died	1	2	3	4	5
20. The best part of me died with the baby	1	2	3	4	5
21. I have let people down since the baby died	1	2	3	4	5
22. I feel worthless since he / she died	1	2	3	4	5
23. I blame myself for the baby's death	1	2	3	4	5
24. I get cross at my friends and relatives more than I should	1	2	3	4	5
25. Sometimes I feel like I need a professional counselor to help me get my life back together again	1	2	3	4	5
26. I feel as though I'm just existing and not really living since he / she died	1	2	3	4	5
27. I feel so lonely since he / she died	1	2	3	4	5
28. I feel somewhat apart and remote, even among friends	1	2	3	4	5
29. It's safer not to love	1	2	3	4	5
30. I find it difficult to make decisions since the baby died	1	2	3	4	5
31. I worry about what my future will be like	1	2	3	4	5

Statement	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
32. Being a bereaved parent means being a "Second-Class Citizen"	1	2	3	4	5
33. It feels great to be alive	1	2	3	4	5

ONLY INDIVIDUALS WHO INDICATED THAT THEY DID NOT SEE A GENETIC COUNSELOR SAW THIS SECTION OF QUESTIONS

1. Were you **offered** genetic counseling prior to your termination of pregnancy for the anomaly found in your pregnancy?
    a. Yes
    b. No
    c. Unsure
2. If you were **not offered** genetic counseling, would you have wanted to see a genetic counselor? (only people who answer "no" or "unsure" will see this question)
    a. Yes
    b. No
    c. Unsure
3. If you were offered genetic counseling, but declined, what was the main reason that you declined? (only people who answer "yes" to the first question in this section will see this question)
    a. Appointment time not available/ did not work with my schedule
    b. I did not want to see a genetic counselor
    c. I did not know what a genetic counselor was
    d. I felt I had enough information from my health care provider
    e. I saw a genetic counselor in the past
    f. Insurance reasons/cost
    g. Other, please explain: _____
4. How helpful do you think seeing a genetic counselor prior to going through termination of pregnancy would have been in helping you to cope post-procedure?
    a. Extremely helpful
    b. Helpful
    c. Neutral
    d. Unhelpful
    e. Extremely unhelpful
    f. I still do not know/understand what a genetic counselor does
    g. I do not know how helpful seeing a genetic counselor would be
5. Would you want to see a genetic counselor in future pregnancies?
    a. Yes
    b. No
    c. Maybe
    d. I still do not know/understand what a genetic counselor does
    e. I am not planning on having future pregnancies
    f. I have seen a genetic counselor in a pregnancy following the one that ended in a termination

6. Please write any other comments about your experience with your healthcare providers prior to undergoing termination of pregnancy for fetal anomaly that you feel are important.

_____

_____

ONLY INDIVIDUALS WHO INDICATED THAT THEY SAW A GENETIC COUNSELOR SAW THIS SECTION OF QUESTIONS

1. What was the reason that you accepted a genetic counseling session? Check all that apply.
    a. My doctor sent me
    b. I wanted more information about the abnormality found in my pregnancy
    c. I wanted more information about whether the same thing could happen in a future pregnancy
    d. I wanted information about genetic testing
    e. I wanted more information about what to expect during the termination
    f. I wanted more information about what to expect after the termination
    g. I wanted psychological support
    h. I wanted information about support groups or resources
    i. Other, please explain: _____
2. What roles did the genetic counselor provide during your session? Check all that apply.
    a. Went over whether the same thing could happen in a future pregnancy
    b. Explained and gave information about the abnormality found in your pregnancy
    c. Provided emotional support
    d. Gave information about genetic testing
    e. Organized genetic testing
    f. Provided support resource information
    g. Discussed expectations of termination
    h. Discussed expectations following termination
    i. Helped coordinate termination
    j. Followed up with you post procedure
    k. Other (please explain): _____
3. Were there any roles that you would have liked your genetic counselor to have filled, that they did not?
    a. No
    b. Yes, please explain _____
4. Were there any roles that the genetic counselor filled that you would have liked them not to?
    a. No
    b. Yes, please explain _____
5. Would you want to see a genetic counselor in future pregnancies?
    a. Yes
    b. No
    c. Maybe
    d. I am not planning on having future pregnancies
    e. I have seen a genetic counselor in a pregnancy following the one that ended in a termination
6. Please explain your answer to the previous question: _____
7. What are your expectations for the role of a genetic counselor in your future pregnancies? Check all that apply
    a. I do not plan on seeing a genetic counselor in future pregnancies
    b. I do not plan on having future pregnancies

c. To go over the chance of the same abnormality happening again in another pregnancy
d. To explain and give information about the abnormality found in your previous pregnancy
e. To provide emotional support
f. To give information about genetic testing
g. To organize genetic testing
h. Other (please explain): _____

8. Did you feel your discussion with the genetic counselor impacted how you coped post procedure?
    a. Yes, in a positive way
    b. Yes, in a negative way
    c. Maybe/Unsure
    d. No
    e. Other
9. Please explain your answer to the previous question.

10. Please write any other comments about your experience with a genetic counselor prior to undergoing termination of pregnancy for fetal anomaly that you feel are important.

*The survey used for this study was created through an online survey tool, Qualtrics. This is a word document version of the survey. The format of the survey that the participants saw differs from what is included in this manuscript.

Appendix D: The Short Perinatal Grief Scale (33-item) Validated Survey

Present Thoughts and Feelings About Your Loss

Each of the items is a statement of thoughts and feelings that some people have concerning a loss such as yours. There are no right or wrong responses to these statements. For each item, circle the number that best indicated the extent to which you agree or disagree with it at the present time. If you are not certain, use the ''neither'' category. Please try to use this category only when you truly have no opinion.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. I feel depressed.	1	2	3	4	5
2. I find it hard to get along with certain people.	1	2	3	4	5
3. I feel empty inside.	1	2	3	4	5
4. I can't keep up with my normal activities.	1	2	3	4	5
5. I feel a need to talk about the baby.	1	2	3	4	5
6. I am grieving for the baby.	1	2	3	4	5
7. I am frightened.	1	2	3	4	5
8. I have considered suicide since the loss.	1	2	3	4	5
9. I take medicine for my nerves.	1	2	3	4	5
10. I very much miss the baby.	1	2	3	4	5
11. I feel I have adjusted well to the loss.	1	2	3	4	5
12. It is painful to recall memories of the loss.	1	2	3	4	5
13. I get upset when I think about the baby.	1	2	3	4	5
14. I cry when I think about him/her.	1	2	3	4	5
15. I feel guilty when I think about the baby.	1	2	3	4	5
16. I feel physically ill when I think about the baby.	1	2	3	4	5
17. I feel unprotected in a dangerous world since he/she died.	1	2	3	4	5
18. I try to laugh, but nothing seems funny anymore.	1	2	3	4	5

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
19. Time passes so slowly since the baby died.	1	2	3	4	5
20. The best part of me died with the baby.	1	2	3	4	5
21. I have let people down since the baby died.	1	2	3	4	5
22. I feel worthless since he/she died.	1	2	3	4	5
23. I blame myself for the baby's death.	1	2	3	4	5
24. I get cross at my friends and relatives more than I should.	1	2	3	4	5
25. Sometimes I feel like I need a professional counselor to help me get my life back together again.	1	2	3	4	5
26. I feel as though I'm just existing and not really living since he/she died.	1	2	3	4	5
27. I feel so lonely since he/she died.	1	2	3	4	5
28. I feel somewhat apart and remote, even among friends.	1	2	3	4	5
29. It's safer not to love.	1	2	3	4	5
30. I find it difficult to make decisions since the baby died.	1	2	3	4	5
31. I worry about what my future will be like.	1	2	3	4	5
32. Being a bereaved parent means being a "Second-Class Citizen."	1	2	3	4	5
33. It feels great to be alive.	1	2	3	4	5

Scoring Instructions

The total PGS score is arrived at by first reversing all of the items except 11 and 33. By reversing the items, higher scores now reflect more intense grief. Then add the scores together. The result is a total scale consisting of 33 items with a possible range of 33–165.

The three subscales consist of the sum of the scores of 11 items each, with a possible range of 11–55.

Subscale 1 *Active Grief*	Subscale 2 *Difficulty Coping*	Subscale 3 *Despair*
1	2	9
3	4	15
5	8	16
6	*11	17
7	21	18
10	24	20
12	25	22
13	26	23
14	28	29
19	30	31
27	*33	32

* Do not reverse.

***Permission was given by the author to utilize this survey tool in this study.** Figures and instructions adapted from: Lori J. Toedter, Judith N. Lasker, Hettie J. E. M. Janssen (2001) INTERNATIONAL COMPARISON OF STUDIES USING THE PERINATAL GRIEF SCALE: A DECADE OF RESEARCH ON PREGNANCY LOSS, Death Studies, 25:3, 205-228, DOI: 10.1080/07481180125971

Appendix E: Brief COPE Validated Survey Tool

Brief COPE

These items deal with ways you've been coping with the stress in your life since you found out you were going to have to have this operation. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't real.".
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been getting help and advice from other people.
11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I've been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.
16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been making jokes about it.
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
20. I've been accepting the reality of the fact that it has happened.
21. I've been expressing my negative feelings.
22. I've been trying to find comfort in my religion or spiritual beliefs.
23. I've been trying to get advice or help from other people about what to do.
24. I've been learning to live with it.
25. I've been thinking hard about what steps to take.
26. I've been blaming myself for things that happened.
27. I've been praying or meditating.
28. I've been making fun of the situation.

Scales are computed as follows (with no reversals of coding):

Self-distraction, items 1 and 19
Active coping, items 2 and 7
Denial, items 3 and 8
Substance use, items 4 and 11
Use of emotional support, items 5 and 15
Use of instrumental support, items 10 and 23
Behavioral disengagement, items 6 and 16
Venting, items 9 and 21
Positive reframing, items 12 and 17
Planning, items 14 and 25
Humor, items 18 and 28
Acceptance, items 20 and 24
Religion, items 22 and 27
Self-blame, items 13 and 26

*This survey tool was adapted from

Carver, C. (1997). You want to measure coping but your protocol' too long: Consider the brief cope. *International Journal of Behavioral Medicine*, *4*(1), 92–100.

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